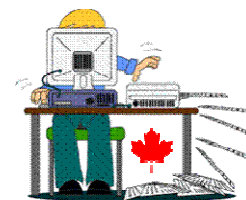


Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Ensuring relevance and consumer-centredness for the expanding palliative care evidence base is essential and can only be achieved through meaningful partnerships with consumer representatives.

'Involving consumers with palliative care needs and their families in research: A case study' (p.9), in *Collegian*.

Canada

Ontario's top court dismisses brain death case but stops short of ruling on key issue

ONTARIO | CBC News (Toronto) – 9 October 2019 – Ontario's top court has dismissed a legal challenge brought by a Toronto-area family that fought to keep their daughter on life support after she was declared brain-dead. But the court of appeal declined to rule on whether accommodations for religious beliefs should be applied to the criteria used to determine that someone has died. In a unanimous decision, the appeal court says that while death is not defined in law federally or provincially in Ontario, common law considers someone dead when there is the irreversible cessation of either cardio-respiratory or brain function. However, it says there is not enough information before the court to settle the issues that form the crux of the case, including whether those criteria constitute a violation of

the right to freedom of religion. The court also noted that the woman at the heart of the challenge, Taquisha McKitty, has since died according to both neurological and cardiovascular criteria, rendering the ruling moot. It says the same questions will likely emerge in other cases, and lays out guidelines on how to assess those arguments in the future... <http://bit.ly/2okXCdB>

Of Related Interest

'When doctors and parents disagree on how to treat a sick child the emotional and financial costs can be huge' (p.6), in *The Conversation*.

Noted in Media Watch 17 December 2018 (#594, p.1):

- ONTARIO | *The Globe & Mail* (Toronto) – 12 December 2018 – '**Ontario family's legal fight to keep daughter on life support could change how death is defined across Canada.**' Ontario has no statutory definition of death; nor do most Canadian provinces and territories. The determination is instead left up to physicians. Doctors use one of two sets of criteria to declare a patient dead: either a stopped heart or a deceased brain. Some Christians, Muslims, Orthodox Jews and members of other religions feel that "brain death" doesn't align with their definition of life's end, especially if technology can preserve tissue, send swells of air into lungs and keep a heart beating. <https://tgam.ca/2SPmp6F>

Palliative care funding becomes more urgent as courts chip away at assisted-suicide safeguards

CANADIAN CATHOLIC NEWS | Online – 7 October 2019 – The Catholic Church is doubling down on its efforts to encourage increased government and societal support for palliative care (PC) as the best way to help Canadians experience a “dignified natural death” as a barrage of Canadian court decisions continue to chip away at the existing safeguards surrounding assisted-dying in the country. “There has been minimal (government support) for PC,” said Winnipeg Archbishop Richard Gagnon, the new president of the Canadian Conference of Catholic Bishops. “There is a great need in Canada for more PC, be that of a religious nature or not.” Gagnon said PC and assisted dying are not two equal options for Canadians nearing the end of life – one, PC, respects the dignity of human life, and the other, assisted dying, does not. “You can assist a person in their last days of life to die with dignity in a

supportive way that respects the importance of life (with PC),” Gagnon said. “The very notion of euthanasia is contrary to that.” One of the issues with PC in Canada is that while the federal government establishes a framework for healthcare in the country, it is the province’s that provide health services in Canada which has led to major differences in how PC is funded in healthcare budgets across the country and how PC services are delivered. <http://bit.ly/2M2A8CI>

[Specialist Publications](#)

‘Palliative care as an emerging role for respiratory health professionals: Findings from a cross-sectional, exploratory Canadian survey’ (p.8), in *Canadian Journal of Respiratory Therapy*.

Noted in Media Watch 24 September 2018 (#582, p.1):

- *THE GLOBE & MAIL* | Online – 19 September 2018 – ‘**Almost all Canadians would benefit from palliative care. Only one in seven can actually access it at end-of-life.**’ An estimated 89% of Canadians could benefit from palliative care (PC) in the last year of life. But only 15% are actually getting it. That’s a pretty damning commentary on the state of end-of-life care in this country, and it only tells part of the story. The new data reveals that even those who get PC tend to get it late, and that far too many dying patients are shuffled around mercilessly between home, hospitals and nursing homes in their final days.¹ The report confirms what far too many people who have accompanied a loved one in their final days know – that Canada is not a very good place to die. <https://tgam.ca/2kpqzTv>

1. ‘Access to Palliative Care in Canada,’ Canadian Institute for Health Information, September 2018. Download/view at: <http://bit.ly/2MqmCYO>

N.B. See ‘Framework on Palliative Care in Canada,’ Health Canada, December 2018. [Noted in 10 December 2018 issue of Media Watch (#593, p.1)] Download/view at: <http://bit.ly/2AVEghF>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The Globe & Mail* – 12 October 2019 – ‘**From dementia to medically assisted death: A Canadian woman’s journey, and the dilemma of the doctors who helped.**’ A confidential decision by the College of Physicians & Surgeons of British Columbia ... has cleared three doctors of wrongdoing [in the medically assisted death of Mary Wilson]. While the word of one province’s medical regulator is not the same as a judicial precedent, the College’s position is likely to reassure doctors who fear they might lose their licences if they hasten the deaths of willing and mentally capable dementia patients. The British Columbia decision is equally likely to horrify opponents of medically assisted death, some of whom worry that pro-assisted-death doctors are pushing the boundaries of Canada’s law too far, possibly endangering vulnerable seniors on the knife’s edge of competency. Either way, Canada is at a political crossroads when it comes to who qualifies for medically assisted dying. <https://tgam.ca/2OFIjrG>



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U.S.A.

Preventing medication diversion in home health and hospice

HEMOCARE | Online – 8 October 2019 – Medical services being provided in the home is a major component of health care in the U.S., and the home setting is fast becoming the preferred site of care for many patients. The home environment, however, may be especially susceptible to the risk of medication diversions – that is, when controlled substances prescribed to a patient are taken and/or used by someone else – because medications aren't as controlled as they are in an inpatient setting. Home health and hospice providers have struggled to effectively identify and care for patients with a history of addiction or substance misuse, and anecdotal evidence suggests that medications are indeed being diverted from some homecare patients. Medications being diverted from hospice patients is especially concerning, as this can increase suffering and pain in the vulnerable time near the end of life. There are several evidence-informed strategies for preventing medication diversion

and misuse in the home. These strategies are a modified version of practice recommendations developed for hospice and community-based palliative care providers. <http://bit.ly/2pUAYCF>

Specialist Publications

'Congenital cardiothoracic surgeons and palliative care: A national survey study' (p.10), in *Journal of Palliative Care*.

'Medical cannabis in palliative care: Meaningful additions to the research evidence' (p.10), in *Journal of Palliative Medicine*.

'Experience and attitudes regarding medical aid in dying ... among Vermont specialty practices' (p.13), in *Journal of Palliative Medicine*.

Noted in Media Watch 23 September 2019 (#632, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(5):365-372. **'State legislation to prevent diversion of opioids in hospice programs: A deeper look into Ohio law.'** Directors of Ohio-licensed hospices were surveyed to assess the percentage of programs with a written policy in place for disposal of opioids and to calculate a compliance score based on responses to survey questions assessing compliance with legislation components. While Ohio Revised Code 3712.062 requires opioid disposal at the time of patient's death or when no longer needed by the patient, only 84% of respondents report disposing opioids upon discontinuation. Overall, a high compliance rate was seen among hospice programs indicating such regulation is manageable to meet. **Abstract:** <http://bit.ly/2m4F4wo>

Noted in Media Watch 11 March 2019 (#605, p.10):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(2):E1-E4. **'Medication safety in hospice and palliative care.'** Medication safety is a top priority, particularly during today's opioids misuse crisis. For every one death from prescription opioids, it is estimated that there are 10 treatment admissions for abuse, 32 emergency room visits for misuse or abuse, 130 people who become dependent on opioids, and 825 people who report non-medical use of these drugs. It is the position of the Hospice & Palliative Nurses Association that medication safety is an essential aspect of hospice and palliative nursing. Hospice and palliative nurses are instrumental in public education about medication safety for patient with serious illnesses, their family, and the community. **First page view:** <http://bit.ly/2ITKvt5>

Many critical care nurses unprepared to provide palliative care

HOSPICE NEWS | Online – 8 October 2019 – Critical care nurses say they feel unprepared to provide palliative care (PC) or hospice care, according to a recent study, underscoring the need to address growing clinical staff shortages in those fields.¹ More than 500 critical care nurses across seven intensive care units in a Virginia-based academic health center responded to a survey designed to measure participants' perceptions of PC in their practice setting. Researchers analyzed responses to a total of 167 completed

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questionnaires, with fewer than 40% of respondents reporting that they were being highly competent in any PC domain. About 38% responded that they had received no PC education within the previous two years. Most respondents reported moral distress during the study period, and moral distress levels differed significantly on the basis of perceived use of PC. Respondents who perceived less frequent use of PC tended to experience higher levels of moral distress. <http://bit.ly/2op3r9L>

1. 'Palliative care and moral distress: An institutional survey of critical care nurses,' *Critical Care Nurse*, 2019;39(5):38049. **Full text:** <http://bit.ly/2oiHlox>

More U.S. heart disease patients may be choosing to die at home

MASSACHUSETTS | Reuters – 7 October 2019 – Fewer U.S. patients with cardiovascular disease are dying in hospitals and more of them are dying at home, a new analysis suggests.¹ Between 2003 and 2017, among the more than 12 million Americans who died of cardiovascular disease, the proportion dying at home rose from 23% to 31%... When investigating how to improve people's last days and hours, researchers have focused on hospital care because most people died there... To take a closer look at how people die in the U.S., researchers [at the Harvard Medical School] merged data from the National Center for Health Statistics and the Centers for Disease Control & Prevention. Focusing on natural deaths with cardiovascular disease as an underlying cause, the researchers broke down the list into categories such as heart attack, stroke and heart failure. Ultimately, they determined that between 2003 and 2017, 12.3 million deaths were attributed primarily to cardiovascular disease. Nearly half, 48.2%, were attributed to coronary heart disease, while 16.7% were due to stroke and 10.6% to heart failure or cardiomyopathy. In 2003, 36.5% of deaths occurred in a hospital, compared to 27.3% in 2017. Deaths at home rose from 21.1% in 2003 to 30.9% in 2017. <https://reut.rs/2lxx0wD>

1. 'Trends in place of death for individuals with cardiovascular disease in the U.S.,' *Journal of the American College of Cardiology*, 7 October 2019. **First page view:** <http://bit.ly/31VRzL0>

Noted in Media Watch 7 October 2019 (#634, p.8):

- **HEALTH EXPECTATIONS** | Online – 27 September 2019 – “**The future is probably now**”: **Understanding of illness, uncertainty and end-of-life discussions in older adults with heart failure and family caregivers.** Clinicians should be aware of what older adults and family caregivers (FCGs) understand about the consequences of their illness to ensure their care plans align with their preferences and needs, as they age and advance in their illness towards the end of life (EoL). Both patients and FCGs experience uncertainty in illness... Future studies are needed to test whether addressing the consequences of illness in HF management can improve understanding of illness and earlier integration of EoL communication for older adults and their FCGs. **Full text:** <http://bit.ly/2nAtcmT>

N.B. Additional articles on palliative and EoL care for patients living with heart failure noted in 19 August 2019 issue of Media Watch (#627, p.10).

Vermont lab uses machine learning to guide palliative care conversations

VERMONT | *Hospice News* – 7 October 2019 – Researchers at the University of Vermont's Conversation Lab are using machine learning to develop algorithms designed to optimize clinician-patient discussions of serious illness, palliative care and end-of-life care. The research team ... has conducted several studies into features of these difficult conversations to identify common characteristics of effective communication that can be replicated. The purpose of the lab is to understand and promote high quality communication in serious illness care, and the spirit of the group is such that we welcome scholars and thinkers from multiple disciplines to think about what an effective conversation is and what a good conversation might look like. In the course of seeking best practices, the group has also identified some potential pitfalls. For instance, they recently determined that clinicians have the tendency to overestimate a patient's life expectancy if the patient and family seem optimistic during discussions of care plans, disease trajectory and the patient's health care goals and wishes. <http://bit.ly/2oouwtx>

Cont.

Noted in Media Watch 22 July 2019 (#623, p.10):

- **HEALTH RESEARCH BOARD: OPEN RESEARCH** | Online – Accessed 15 July 2019 – **‘Improving palliative and end-of-life care with machine learning and routine data: A rapid review.’** In clinical practice, physician judgement is the core method of identifying end-of-life care needs, but has important limitations. Machine learning (ML) is a subset of artificial intelligence advancing capacity to identify patterns and make predictions using large datasets. ML approaches have the potential to improve clinical decision-making and policy design, but there has been no systematic assembly of current evidence. ML has the potential to support clinicians in improved decision-making by identifying those at heightened risk of inappropriate care, poor outcomes and mortality. **Full text:** <http://bit.ly/2LUETyU>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON | Yahoo Finance – 9 October 2019 – **‘Federal study finds nation's assisted suicide laws rife with dangers to people with disabilities.’** The National Council on Disability (NCD) released the findings of a federal examination of the country's assisted suicide laws and their effect on people with disabilities, finding the laws' safeguards are ineffective and oversight of abuses and mistakes is absent.¹ Despite the belief that pain relief is the primary motivation for seeking assisted suicide, the NCD found that the most prevalent reasons offered by someone requesting assisted suicide are directly related to unmet service and support needs, which NCD urges policy makers respond to through legislative changes and funding. <https://yhoo.it/2Vstl8L>

1. ‘Assisted Suicide Laws and their Danger to People with Disabilities,’ National Council on Disability, October 2019. **Download/view at:** <http://bit.ly/2pX5uCd>

International

How can children be taught about death and serious illness?

GERMANY | Aljazeera – 10 October 2019 – The children at Kita Entenhausen Bruchhausen, a kindergarten in Arnsberg, West Germany, are playing on the swings. When they are called back inside, some protest, but they perk up when they realise that it is reading time. Anni Kunkenrenken, a 75-year-old volunteer at the kindergarten, welcomes them inside with a picture book which she reads about opa (grandpa in German), who visits an island and does not return. The book subtly portrays the death of a grandparent in a story about travel, which the four to six-year-olds listen to attentively until the end. She picked the book from Kita Entenhausen Bruchhausen's library, which has 200 children's titles on ageing, dying and dementia. Two decades ago, when Arnsberg started bracing itself for demographic changes, Ulla Huser, the head of the kindergarten, opened the library with a modest offering of 10 books. Arnsberg – like all of Germany – has a large and growing elderly population. When children's grandparents died, Huser said they often sought support at the kindergarten. Ten years ago, after the city launched its Fachstelle Zukunft Alter, or the department of

Future of Ageing, the kindergarten received funding to add books that tackled the topic of dementia. “Children feel for people in need,” says Professor Dr. Andreas Kruse, director of Gerontology at the University of Heidelberg. “They can emotionally support them, with their special kind of sympathy.” Introducing children to subjects including dementia and dying in school or even kindergarten can be a positive experience, he says. <http://bit.ly/2VsJpgQ>

Specialist Publications

‘Quality of life and symptom intensity over time in people with cancer receiving palliative care: Results from the international European Palliative Care Cancer Symptom study’ (p.12), in *Plos One*.

‘Autonomy and dying: Notes about decision-making and “completed life” euthanasia in The Netherlands’ (p.13), in *Death Studies*.

Cont.

Noted in Media Watch 10 December 2018 (#593, p.6):

- **EDUCATIONHQ** | Online – 3 December 2018 – ‘**English, maths and death? Doctors call for death ed in schools.**’ The Australian Medical Association of Queensland (AMAQ) is calling for more education around death and dying, and want the discussion to start in schools. AMAQ has proposed an addition to the Australian curriculum to help young people cope with loss and demystify the end of life (EoL). Dr Richard Kidd says it shouldn't sound as outlandish as it might. The chair of general practice says his members have seen too many tragic incidences where young people were left to contend with the consequences of a death with little in the way of preparation. **Full text:** <http://bit.ly/2kQl40n>

N.B. Additional articles on the topic of dying and death in the school curriculum noted in this issue of Media Watch.

When doctors and parents disagree on how to treat a sick child the emotional and financial costs can be huge

U.K. | *The Conversation* – 9 October 2019 – When a child is sick and parents and doctors disagree about what to do next, who is best placed to make that decision? This is a tricky but not uncommon question – with a number of recent high-profile legal cases highlighting the limits of parents' rights to decide what treatments should be offered. The issue has been brought into the spotlight again after the parents and healthcare team of Tafida Raqeeb disagreed about whether she should be offered life-sustaining treatment.¹ Tafida's parents wanted to take her to Italy for treatment, but a spokesperson for Barts Health National Health Service (NHS) Trust, where she is being cared for, said that: “further medical treatment would not improve her condition.” The High Court ruled that “life-sustaining treatment” for Tafida must continue – and Barts NHS Trust's application to withdraw life support was dismissed. Tafida's parents argued that under Islam only God can make the decision to end her life, and so they wished to continue treatment. Conflicts between parents of very sick children and hospital staff are not uncommon, and often become high-profile when legal interventions are triggered. Tafida's case is typical of healthcare conflict – clinicians are reluctant to offer treatments that are likely to be futile and parents are desperate to try everything for their child – even if the odds of success are low. At the heart of such cases is a breakdown in communication between the clinicians and the family about what is in the child's best interests – so the law intervenes when relationships fail. I've been conducting research for many years in the field of healthcare conflict in children's hospitals, and other healthcare settings, including adult palliative care.² Families losing trust in clinicians is a key cause of conflict – along with poor communication and different ideas about the goals of care for a child. <http://bit.ly/33hF50o>

1. ‘Tafida Raqeeb: Brain-damaged girl can go abroad for treatment,’ BBC News, 3 October 2019. <https://bbc.in/2M2sR5W>
2. ‘The conflict pathway: a model to address conflict in paediatric practice,’ *Archives of Disease in Childhood*, 24 May 2012. **Abstract:** <http://bit.ly/33jotFx>

Noted in Media Watch 22 April 2019 (#611, p.3):

- **ARCHIVES OF DISEASE IN CHILDREN** | Online – 18 April 2019 – ‘**Achieving consensus: Advice for paediatricians and other health professionals on prevention, recognition and management of conflict in paediatric practice,**’ Conflict is damaging, stressful and emotionally challenging for all involved. Taking the correct early steps may prevent early disagreements reaching conflict. If conflict is reached, families must continue to be supported even if there is a breakdown of trust between families and clinicians. As the voice of the child and what is in their best interest remains paramount, the families' wishes and needs must also be taken into consideration. **Full text:** <http://bit.ly/2T4Zwd6>

82% of charitable hospices planning deficit budget this financial year

U.K. (England) | UK Fundraising – 7 October 2019 – Eight out of ten (82%) of charitable hospices surveyed by Hospice UK are planning a deficit budget this financial year according to figures issued by the charity.¹ Hospice UK says funding for the U.K.'s 200 charitable hospices is on a knife-edge and that care for dying people needs to stop being so reliant on local fundraising, pointing out that earlier this year two hospices were forced to close and others have had to cut services or jobs. Last month the government announced a £25 million cash injection for charitable hospices and palliative care providers in England. At the time the Prime Minister also promised to conduct a more detailed review of funding for end-of-life (EoL) care. Hospice UK is now calling on the government to follow through on its earlier commitment and bring this forward. The charity says that funding for the EoL care system as a whole, including hospices, is “broken” and that a sustainable solution needs to be developed urgently, especially to meet fast growing demand for this care. Earlier research by Hospice UK shows that more than 100,000 people are unable to get the support they need at the EoL across all care settings, while more than 40% of care home residents, many of whom have complex needs associated with the EoL, are forced to pay for their care under current rules. <http://bit.ly/33eXAx>



1. 'Eight in ten charitable hospices planning a deficit budget this financial year,' Hospice UK, September 2019. <http://bit.ly/2obgnA9>

Noted in Media Watch 23 September 2019 (#632, p.8):

- **BRITISH MEDICAL JOURNAL** | Online – 18 September 2019 – ‘£25 million for hospices won’t go far.’ Last month the prime minister pledged a one-off payment of £25 million (€28 million; \$31 million) to boost hospices and palliative care services. Within a day of the announcement, however, the chair of National Health Services (NHS) Clinical Commissioners told the *Health Service Journal* that the £25 million would come from ring-fencing existing NHS budgets, inevitably at the expense of other cash starved services.¹ Some 73% of respondents to a recent Hospice UK survey had seen the funds they received from clinical commissioning groups frozen or cut, although their own costs were rising.² One in three had been forced to cut services, and around half had delayed or cancelled plans to develop or expand them. **Full text:** <http://bit.ly/2IW27cS>

1. 'Funding boost for hospices promised by prime minister is not new money,' *Health Service Journal*, 21 August 2019. **Introduction:** <http://bit.ly/2mpqOyN>
2. 'U.K. hospices face funding crisis as one in three forced to cut end-of-life services,' ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] <http://bit.ly/3071bSA>

Consultation brings death into the open

CHINA (Hong Kong) | *South China Morning Post* – 6 October 2019 – Having studied the issues for years, the government has finally released a public consultation on end-of-life care (EoLC). This includes legislative changes to enable patients to give clear advance directives (ADs) on treatments and to facilitate EoLC outside hospitals. Ever since the Hospital Authority has issued guidelines in line with relevant recommendations made by the Law Reform Commission, the number of ADs given by patients rose from an annual 150 in 2012 to more than 1,500 last year. But there is still much room for improvement in terms of awareness and acceptance. A survey in 2016 showed that nearly nine in 10 respondents had not heard of such a concept. Given the options involve fundamental changes to existing law and practices, a host of issues have to be rationalised. The issues are especially pertinent in our fast ageing society. By 2066, one in three people will be aged 65 or above; and the annual number of deaths will hit 98,000, up from the existing 46,700 in 2016. The trend inevitably adds pressure to public finance in the long run if dying in hospital, which currently accounts for 96% of deaths, remains the default option. <http://bit.ly/2obliB7>



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N.B. Hong Kong is ranked 22nd of 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** <http://bit.ly/30YoDKl>

Specialist Publications

Volunteers in a biography project with palliative care patients: A feasibility study

BMC PALLIATIVE CARE | Online – 7 October 2019 – Increasing the quality of life with short interventions for vulnerable patients is one of the objectives of palliative care (PC). Biographical approaches are used in a range of different interventions which may require considerable resources of staff time and energy. This study evaluated the feasibility of training hospice volunteers in biographical interviews of patients confronted with a life-limiting disease. For the purpose of this study, the authors evaluated resources such as time needed for training, coordination and supervision, outcome such as completion of the intervention in appropriate time and risks such as causing distress in patients or volunteers as major determinants of feasibility. This study confirmed that biography training for volunteers was feasible and enabled volunteers to perform biographical interviews with PC patients. The engagement of trained volunteers can ensure sustainability of the provision of biography work. Patients appreciated the attention they received, and volunteers felt that their involvement was personally rewarding. Volunteers required supervision and ongoing support in providing this intervention. **Full text:** <http://bit.ly/2Vllp9e>

Noted in Media Watch 16 February 2015 (#397, p.8):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 12 February 2015 – ‘**The lived experience of volunteering in a palliative care biography service.**’ Volunteering gave the volunteers [i.e., participants in this study] a deeper appreciation of existential issues, and helped them to be more appreciative of their own lives and gain a deeper awareness of the struggles other people experience. They also suggested that volunteers felt that their involvement contributed to their own personal development, and was personally rewarding. Furthermore, the results highlighted that volunteers found that encounters with family members were sometimes challenging. While some were appreciative, others imposed time limits, became overly reliant on the volunteers, and were sometimes offended, hurt, and angered by what was included in the final biography. **Abstract (w. list of references):** <http://bit.ly/30Z8QBw>

Palliative care as an emerging role for respiratory health professionals: Findings from a cross-sectional, exploratory Canadian survey

CANADIAN JOURNAL OF RESPIRATORY THERAPY, 2019;55:73-80. As key members of the health-care team, respiratory health professionals (RHPs) have significant influence over the quality of care (QoC) and an emerging opportunity to influence quality exists in the area of care in advanced respiratory disease. Incorporating a more defined role in palliative care (PC) was seen by most respondents as a desirable evolution in professional responsibility, particularly given that deaths of respiratory patients were not uncommon on caseloads, and there was variability in access to PC services across Canada. Variability in RHPs practice with respect to discussing preferences for end-of-life (EoL) care was noted, as was the use of advance care plans. The most important patient- and family-related barriers to having EoL discussions included difficulty accepting prognosis, limitations, and complications, as well as patient lack of capacity. For providers, the most important barriers to having these discussions were lack of training, uncertainty about prognosis, and lack of time. Important opportunities to improve the QoC at the EoL exist in closer collaboration between RHPs and formal palliative services and participation in providing support patient transitions between settings. Chronic disease management and PC were not viewed by respondents as mutually exclusive foci of care, but could be integrated to better address the needs of patients. The authors’ findings support imperatives to incorporate a palliative approach into the care of patients with advanced respiratory disease, which have been framed from the perspectives of both justice and redressing health care disparities. **Full text (via PubMed):** <http://bit.ly/2lEw75H>

N.B. Additional articles on palliative and end-of-life care in individuals with respiratory diseases noted in 5 August 2019 issue of Media Watch (#625, pp.7-8).



Closing the Gap Between Knowledge & Technology
<http://bit.ly/2DANDFB>

Involving consumers with palliative care needs and their families in research: A case study

COLLEGIAN | Online – 7 October 2019 – There are significant policy imperatives to involve consumers at the outset of and throughout research. How best to achieve this in an authentic and meaningful way is elusive, particularly within the palliative care population. In this study, eleven consumers contributed across five panel meetings. Analysis of documented feedback led to four key areas of protocol change: 1) Getting the language in the recruitment materials and information and consent forms right; 2) Developing a feasible and acceptable recruitment strategy; 3) Opportunities to more clearly articulate the explicit value of this research for patients and families; and 4) Support strategies for participants. Authentic consumer engagement requires time and effort; however, the outcomes are well worth the invested time and energy. Key foci outlined within this case study to enhance authenticity included: collaboration; preferring the consumer voice; adequate preparation to support consumer engagement; and openness to all feedback provided. Co-designing research with consumers enabled the outcome to be feasible for implementation, without any modifications required. **Abstract:** <http://bit.ly/2M1kyHC>

Noted in Media Watch 19 February 2018 (#551, p.11):

- *COLLEGIAN*, 2018;25(1):1-2. ‘**Research involving dying persons: Time to reconsider?**’ Research involving the dying, whether conducted in palliative care settings or elsewhere, is often considered ethically challenging and controversial. This is because of concern about the actual or potential vulnerability of persons approaching the end of life and whether the dying person can or should be involved in research. Yet, the caution associated with research participation for those who are dying, might need to be reconsidered. Despite concern from ethical review boards, researchers, clinicians and consumers that research involving dying persons might be intrusive, inappropriate or unethical, the research evidence suggests that dying persons who have participated in research did so with very good reason. **Full text:** <http://bit.ly/2OEihUv>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 October 2019 – ‘**Challenges in implementing hospice clinical trials: Preserving scientific integrity while facing changing environments.**’ Numerous changes can occur between the original design plans for clinical trials, the submission of funding proposals, and the implementation of the clinical trial. In the hospice setting, environmental changes can present significant obstacles, which require changes to the original plan designs, recruitment and staffing. The purpose of the paper is to share lessons and problem-solving strategies that can assist in future hospice trials. **Abstract (w. link to references):** <http://bit.ly/2pcVcxA>

The AMBER care bundle for hospital inpatients with uncertain recovery nearing the end of life: The ImproveCare feasibility cluster randomized controlled trial

HEALTH TECHNOLOGY ASSESSMENT, 2019;23(55):1-150. Unwell hospital patients who are approaching the end of their lives and may die at any moment receive inconsistent care and often do not have opportunities to discuss their future care preferences. The AMBER (Assessment; Management; Best practice; Engagement; Recovery uncertain) care bundle was developed to help identify such patients, train healthcare professionals to better communicate their concerns with them and their families and, where possible, to realise their preferences for place of care and death. The AMBER care bundle ... aims to provide better outcomes for patients with clinically uncertain recovery and their families. It is important that the AMBER care bundle is properly investigated before wider use. A bigger study of the AMBER care bundle would be complex and expensive, so the authors examined whether or not this would be possible and acceptable to patients cared for in four wards across four hospitals, before deciding whether or not to go ahead with this bigger study. Two wards used the care bundle and two did not. The authors interviewed participants, their families and staff, and examined participants’ clinical notes. They found that the AMBER care bundle was largely acceptable to patients, relatives and staff, and generally delivered as intended. Group discussions with staff and interviews with participants and relatives identified important changes required to improve the AMBER care bundle and views on how the trial was conducted. These included simplifying the type of patients who may be appropriate for the AMBER care bundle and improving communication training for staff. The AMBER care bundle continues to be used in over 40 hospitals in England. **Full text:** <http://bit.ly/2IEBkuh>



Congenital cardiothoracic surgeons and palliative care: A national survey study

JOURNAL OF PALLIATIVE CARE | Online – 9 October 2019 – The majority of children with advanced heart disease in the inpatient setting die in an intensive care unit under 1 year of age following multiple interventions. While pediatric cardiology and palliative care (PC) provider attitudes have been described, little is known about pediatric cardiothoracic surgeon attitudes toward PC in children with advanced heart disease. Almost all (90%) of survey respondents reported that they had experience consulting PC. While 68% felt PC consultation was initiated at the appropriate time, 29% felt it occurred too late. When asked the appropriate timing for PC consultation in hypoplastic left heart syndrome, 45% selected “at time of prenatal diagnosis” and 30% selected “when surgical and transcatheter options have been exhausted.” Common barriers to PC involvement included the perception of “giving up” (40%) and concern for undermining parental hope (36%). While a majority of pediatric cardiothoracic surgeons [i.e., survey respondents] are familiar with PC, there is variation in perception of appropriate timing of consultation. **Abstract:** <http://bit.ly/3261Mo7>

Related

- *JOURNAL OF PEDIATRIC HEALTH CARE* | Online – 5 October 2019 – ‘**The impact of provider education on pediatric palliative care referral.**’ Educational sessions outlining national referral recommendations were offered to providers in the neonatal intensive care unit, pediatric intensive care unit, and Center for Cancer & Blood Disorders at a tertiary care facility [in Phoenix, Arizona]. Presurveys and post-surveys were administered at the time of the intervention, and referral rates for the organization were collected for two months before and two months after the intervention. While there was a clinically significant increase in hospital-wide referral rates, most important was the statistically significant increase in provider comfortability with established guidelines. **Abstract:** <http://bit.ly/335VL15>

Medical cannabis in palliative care: Meaningful additions to the research evidence

JOURNAL OF PALLIATIVE MEDICINE, 2019; 22(10):1173-1174. Palliative care (PC) team members need to understand what is known and unknown about cannabis’s health effects for individuals with high physical, emotional, or existential symptom burden because cannabis use is increasing even though healthcare practitioners may feel unprepared to counsel their patients. As of June 2019, [in the U.S.] 33 states and the District of Columbia have legalized medical cannabis use, and 11 states and the District of Columbia have legalized recreational cannabis use among adults. Use is permitted in other countries around the world, including Canada, The Netherlands, and Germany. The current issue of the *Journal of Palliative Medicine* provides a robust compilation of eleven articles focusing on medical cannabis use in PC. Together, these studies provide meaningful additions to the research evidence. The settings range from children’s hospice in the U.K. to a rural academic outpatient PC clinic in Western New Hampshire.

Several studies address patients living with cancer, including those seen at comprehensive cancer centers, outpatient palliative medicine programs, or individuals with and without cancer who obtained cannabis through a large medical cannabis dispensary in New York. **Full text:** <http://bit.ly/30RnRp6>



N.B. Additional articles on medical cannabis in PC noted in 9 September 2019 issue of Media Watch (#630, pp.12-13).

Video advance directives: A turning point for advance decision-making? A consideration of their roles and implications for law and practice

LIVERPOOL LAW REVIEW | Online – 5 October 2019 – Questions regarding assessing the validity, applicability and authenticity of these video advance directives (ADs) raise important issues when they are called into implementation. Such a consideration is timely given the progressive shift towards electronic options of making and recording ADs. There are important implications for jurisdictions wishing to implement the law on ADs with the need to take into account these developments in the formulation of their law and the compatibility with current practices, particularly the ways in which the existing framework accommodates the challenges arising from video ADs. While video ADs have several advantages over written ADs, they suffer from issues regarding the validity of the AD and the opportunity to review the decision, in addition to practical questions on storage, security and accessibility. Despite this weakness, they complement written ADs in their supplementary roles, as such there are opportunities to investigate other ways in which video ADs can assist advance care planning processes and consequently for hospitals to offer training and support to healthcare professionals in facing these concerns. Additionally, it is particularly significant to note that there is still a need to understand who the in-

tended service users are and how video ADs can play an effective role in facilitating the implementation of their preferences. This includes broader questions regarding the awareness of the population in using video ADs, and familiarity with managing online registries or cloud storage. **Full text:** <http://bit.ly/31TtEMi>

Extracts from *Liverpool Law Review* article

The authenticity of video ADs is an important implication, as it raises both legal and ethical considerations. How authentic are these expressions of wishes projected through videos?

Access to ADs is a major challenge in clinical practice often linked to the ways they are stored or the lack of awareness regarding their existence. They may not be found or, if found, discovered too late while decisions were made and treatments continued to be administered.

As with written ADs, video ADs need periodic reviews, and particularly necessary where circumstances have changed requiring different considerations. The issue here then is to what extent should the video recording be re-recorded when circumstances have changed?

Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 10 October 2019 – ‘**Is a spectrum the best metaphor for leading advance care planning discussions?**’ The metaphor of a spectrum is reviewed and critiqued as a clinical tool to help patients identify if medical care preferences should be more focused toward comfort or life-prolongation. An alternative metaphor of an equalizer for an audio sound system is proposed as a potentially more appropriate metaphor to help clinicians appreciate the complex mix of patient values and care preferences that often are driving patient decision-making in the context of a life-limiting illness. **Abstract:** <http://bit.ly/2OB60jA>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 October 2019 – ‘**Leveraging In-Home Supportive Services programs to engage people in advance care planning: Input from staff, providers, and client stakeholders.**’ In-Home Supportive Services (IHSS) cares for millions of Medicaid-eligible older adults [in the U.S.] who are often homebound and socially isolated. Advance care planning can be challenging for this population, and IHSS programs may play an important role. Implementation suggestions for success by IHSS stakeholders include focusing on case managers rather than in-home caregivers to prevent conflict of interest; tailoring programs to clients' readiness, literacy, and language; creating educational programs for IHSS staff, clients, and community; and standardizing easy-to-use guides and procedures into IHSS workflows. **Abstract:** <http://bit.ly/2AZYK95>

Exploring the implementation of family-witnessed resuscitation in children and young people

NURSING CHILDREN & YOUNG PEOPLE | Online – 30 September 2019 – There are varying opinions about family-witnessed resuscitation (FWR) in children and young people throughout the literature and the guidance on this practice is outdated and imprecise. FWR can have psychological benefits for relatives; however, healthcare practitioners are often prevented from implementing this practice because of the perceived negative effect on their work through distraction or interference. Healthcare practitioners can also find it challenging to negotiate the ethics of FWR, particularly in relation to whether this practice can be considered caring or compassionate. The limited guidance on FWR in children and young people also means that it can be challenging for healthcare practitioners who want to implement the practice to identify available evidence to justify their actions. This article explores the evidence for and against the practice of FWR in children and young people and provides recommendations for healthcare practitioners who are implementing this practice. **Abstract:** <http://bit.ly/2LRHXLy>

Noted in Media Watch 1 January 2018 (#544, p.16):

- *JOURNAL OF CLINICAL NURSING* | Online – 20 December 2017 – ‘**How do clinicians practice the principles of beneficence when deciding to allow or deny family presence during resuscitation?**’ The decision to allow or deny family presence during resuscitation is complex and often impacted by personal preferences and beliefs, setting norms and tensions between clinicians and consumers. As a result, many families are missing the chance to be with their loved ones at the end of life. The findings of this study highlight current deficits in decision-making around family presence during resuscitation and could prompt the introduction of clinical guidelines and policies and in turn promote the equitable provision of safe, effective family-centred care during resuscitation events. **Ab-stract:** <http://bit.ly/31QoXme>

N.B. Additional articles on family presence during cardiopulmonary resuscitation are noted in 7 August 2017 issue of Media Watch (#524, p.13).

Quality of life and symptom intensity over time in people with cancer receiving palliative care: Results from the international European Palliative Care Cancer Symptom study

PLOS ONE | Online – 9 October 2019 – The European Palliative Care Cancer Symptom (EPCCS) study is the largest international, longitudinal study in a palliative care (PC) cancer population of which the authors are aware. Strengths of this research include the prospective design, the sample size and the inclusion of patients from multiple centres, which made it possible to follow quality of life (QoL), emotional functioning (EF), physical functioning (PF) and symptoms over an extended period of time, in a considerable number of vulnerable people in Europe and beyond. The linear mixed model procedure adopted in this study is a powerful approach as it takes account of repeated measurement and clustering effects at both hospital and country level. Despite these strengths, the study also has limitations which need to be acknowledged. The first concerns the representativeness of the sample. The EPCCS study's main report showed that there is large variation in the organization and delivery of PC services and in patient characteristics (e.g., primary tumor sites, stages and treatment regimens) across Europe. Clear population criteria will be essential in future research to facilitate the com-

parison of results across different studies and countries. A second notable issue is that data were relatively sparse in the last months of the study. Patient attrition is an inherent difficulty of longitudinal studies, especially in PC where drop out due to deterioration or death is very likely. Third, it is possible that participants with the worst levels of functioning were not included in the study, which may have resulted in an underestimation of the QoL and symptom experience. **Full text:** <http://bit.ly/2OHjs5P>

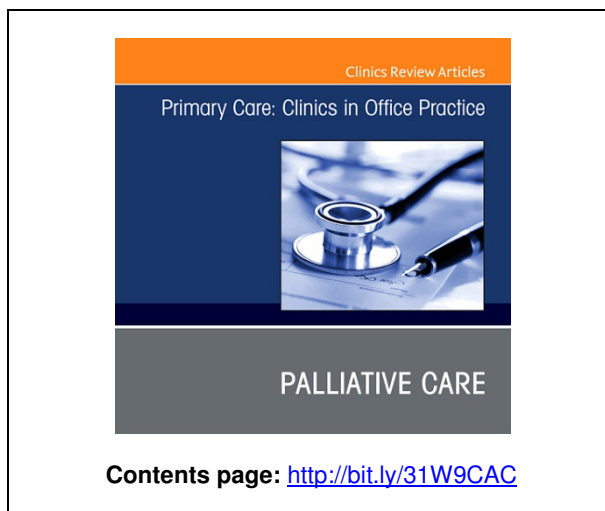
Extract from the *Plos One* article

While the prospective approach showed predominantly stable patterns for quality of life, functioning and symptom severity throughout study duration, retrospective analyses indicated that deterioration was already apparent before the terminal phase and accelerated close to death. Our findings support the importance of early symptom identification and treatment in this population, and highlight the need for further studies to explore what characterizes those with either lower or higher symptom burden at different time points towards death.

Focus on palliative care

PRIMARY CARE: CLINICS IN OFFICE PRACTICE, 2019;46(3):xv-xvii. This issue offers a comprehensive and detailed source of information on palliative care (PC). It begins with the introduction of basic PC skills, such as pain and non-pain symptom management, and moves forward to highlight the important role of prognostication in formulating goals of care. The issue then addresses more complex domains, such as the psychosocial, ethical issues, and communication skills needed to care for people with serious illness. Additional articles focus on PC from the pediatric to the geriatric age group as well as a disease-oriented approach to chronic complex illness, such as congestive heart failure, chronic obstruction pulmonary disease, and HIV/AIDS. An article on the role of the primary care provider in hospice care highlights the need for all primary care providers to obtain primary PC skills and maintain a continuity of

care relationship until the end of life. **Preface:** <http://bit.ly/33erhnj>



Contents page: <http://bit.ly/31W9CAC>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *DEATH STUDIES* | Online – 10 October 2019 – ‘**Autonomy and dying: Notes about decision-making and “completed life” euthanasia in The Netherlands.**’ Euthanasia in The Netherlands is based on the notion that the person seeking assistance to die is able to make an autonomous decision. This study explores this notion, in particular, in the case of “tiredness of life” ... based on two qualitative researches and two selected case histories that provide an in-depth insight into the complex process of (not) reaching a clear decision. The authors found three obstacles that cast doubt over autonomous decision-making in the face of death: 1) Doctors – not patients – have the final say in “measuring” the “amount” of pain and suffering that entitles a person to be granted euthanasia; 2) Human decisions are always taken in a context of complex circumstances involving relatives, friends, and medical professionals; and, 3) People lose much of their autonomy when they grow old and fragile, and will be increasingly inclined or forced to leave decisions to others. **Abstract:** <http://bit.ly/2M1NjUJ>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 8 October 2019 – ‘**Experience and attitudes regarding medical aid in dying ... among Vermont specialty practices.**’ In 2013, the Vermont legislature passed the ‘Patient Choice & Control at End-of-Life Act’, which legalized medical aid in dying (MAiD) under specific circumstances for terminally ill Vermont residents. In the five years since the law was passed, 52 patients in Vermont have been prescribed medications to hasten death; however, important information regarding the experiences of the patient, caregiver, or physician involved in this process is lacking. 71% of the survey participants supported MAiD; however, many felt that they could use more information and resources to counsel a patient (51.4%) and complete the paperwork and prescription for life-ending medication (37.4%). This is the first study to collect information regarding physicians’ attitudes and experiences regarding Act 39 in Vermont. **Abstract:** <http://bit.ly/320jb1x>

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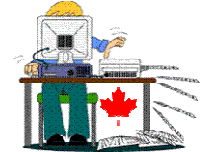


Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

- *REVUE INTERNATIONALE DE SOINS PALLIATIFS*, 2019;34(2):37-44. ‘**Nurses and assisted suicide: Valuing well-being.**’ The findings of the authors’ literature review show that factors influencing the demand for assisted suicide (AS) are mainly inherent and intrinsically linked to the patient’s personality. Health care professionals are not well informed about the institutional and legal provisions regarding AS. Willingness to be involved in the process varies depending not only upon their personal beliefs but also upon their level of knowledge. Identifying the factors that influence the application for AS highlights the need for the autonomy and the monitoring of the people making the application. Due to the lack of an institutional and legal framework, carers often feel helpless in these situations. Some ideas are proposed about the nursing role to promote the well-being of people, drawing upon The findings of this literature review should be considered with caution in view of the limited available literature on the subject and the small number of articles considered. **Abstract:** <http://bit.ly/2AUKhev>

N.B. French language article.



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

[Media Watch: Editorial Practice](#)

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2p0p68g>

[Scroll down to 'Media Watch: Long-Term Care']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

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[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

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[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

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HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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